

## Editors' Introduction

Where does the responsibility for quality and care in an individual's experience of illness lie? In this issue, several authors explore different dimensions of illness experience, including diagnosis, treatment and caregiving. The investigations involve different actors—doctors, patients, regulators, industry, caregivers, and even social scientists themselves—and come from divergent perspectives, resulting in a rich and reflexive set of analyses that unsettle simplistic notions of blame and responsibility, agency and activism, in illness experiences.

Janice Graham dissects the regulatory and clinical processes that surrounded the controversial decision by NICE in 2006 to discontinue National Health Service funding of cholinesterase inhibitors (ChEI) therapy for those with diagnoses of early stage Alzheimer's disease. Graham's analysis points to the importance of 'regulatory facilitation'—productive negotiation amongst a variety of actors representing competing interests—in the delivery of evidence-based medicine and quality healthcare. Indeed, the importance of human interactions (as compared to the manipulation of statistical models, clinical trials or biomedical technologies), in delivering quality care is central to the article by Kleinman and Hanna. Drawing on a combination of personal experiences and an analysis of physician education and training, these authors argue persuasively that caregiving is an increasingly separate sphere in a process of medical education that focuses on training students to interact with complicated machines rather than with sick human beings. Caregiving and engagement with individuals' illness experiences are increasingly the domain of nursing—and of social science, as Chloe Silverman points out in her review of social science perspectives on autism. Silverman's review not only raises significant issues about the conceptual and theoretical orientations that identify autism as a 'project' worthy of social science scrutiny, it also makes the compelling suggestion that social scientists studying autistic individuals owe an obligation of care to their 'subjects'. Silverman suggests that researchers endeavour to approach vulnerable participants in autism research in 'friendship' first, thus creating a space of care, before striking the research bargain. The complexities of the relationship between social science researchers and participants in mental health-related research are also raised repeatedly in this issue's Books Forum, where the fluid and reflexive relations between 'researcher' and 'researched' are made startlingly clear in a series of insightful reviews of three important books on psychiatry and psychiatric illness.

The negotiations, contestations and relations amongst various actors are also key features in the three articles in this issue that focus on the challenges and promises raised by the rapid developments in synthetic and molecular biology. In his report on the EU-funded PAGANINI project (Participatory Government and Institutional Innovation), Herbert Gottweis demonstrates the extent to which 'participatory governance' involves artificial representations of 'the public' and strategically constructed interactions between these publics and institutions or government. However, individual citizens are not the only ones being effortfully mobilized into political action in this age of biological control; scientists too feel compelled to engage in participatory activities. In a provocative roundtable discussion, synthetic biologists Jef Boeke and Drew Endy admit to social scientists Gaymon Bennett, Filippa Lentzos and Paul Rabinow, that their interactions with social scientists, policy makers and the public are purposeful: this interaction is the only way to create the kind of

understanding about the scientific work that will ensure continued public funding and support. Hans Jörg Rheinberger's short article on the history of molecular biology suggests that this increasing 'orientation toward the market' in science has deep consequences for scientific disciplines themselves, leading potentially to their devaluation and ultimate dissolution.

We hope you find the issue as exciting as we do. We continue to welcome any thoughts and comments you might have on the particular contributions in the issue, or on the social, ethical, legal, economic, public or policy aspects of current and emerging developments in the life sciences more generally.

# **VITAL POLITICS III**

## ***The Politics of the Life Sciences in an 'Age of Biological Control'***

16–18 September 2009

London School of Economics and Political Science  
CALL FOR PAPERS

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The BIOS Centre for the Study of Bioscience, Biomedicine, Biotechnology and Society is organizing an international conference on 16–18 September 2009 at the London School of Economics and Political Science. The aim of the conference is to provide a comparative and global perspective on present forms of practice in the life sciences. The Organizing Committee welcomes proposals for individual papers which seek to make empirically based and conceptually innovative contributions to the exploration of the character and genealogy of transformations in health, illness, vitality, pathology and politics. We particularly welcome papers that relate to the themes below, however we are also happy to consider contributions which address the topic of the conference but may not align with these themes.

### **Biological Citizenship in a Global Political Economy**

This theme includes biosocial identities and solidarities at the global scale, especially relating to global health inequalities or orphan diseases; the sustainable and democratic governance of the life sciences, and the challenges of public policy making in conditions of uncertainty; the impact of these policies on the formation (and transformation) of biological citizenships, in particular relating to identity, gender, or ethnicity; analyses of the pharmaceutical industry, its management and regulation in a globalized world.

### **Identities and Power in a Neuro-Age**

This theme includes explorations of the ways in which recent developments in neuroscience such as psychiatric genetics, psychopharmacology, neuroimaging and other brain technologies are changing power dynamics between state, industry, expertise and consumers, patients, children, parents, employees and offenders; analyses of the role of neuro-expertise, the problems of uncertainty and strategies of risk assessment in the context of regulation and control of the neuro-technologies and the rise of 'neuro-markets'; examinations of the impact of neuroscience on categorization in psychiatric disorders, and on shifting patterns in 'normalcy' and 'pathology'.

## **Biopolitics in an Age of Regenerative and Synthetic Technologies**

This theme includes explorations of politics and ethics in relation to synthetic biology and regenerative medicine; research on the ways in which developments in these areas are changing conceptions of self, identity and embodiment; analyses of the political and ethical frameworks guiding biomedical research and interventions in the 'age of regeneration' and in the light of concerns about biosecurity; research on the socio-political and ethical aspects related to biosecurity, bioengineering and the markets for DNA, tissues, organs and other synthetic devices.

**Please submit abstracts (250–300 words) by e-mail to [v.dyas@lse.ac.uk](mailto:v.dyas@lse.ac.uk)**

**Deadline for abstract submissions: 1 December 2008**

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